

## PLEASE NOTE:

This email is completely and totally  
**unofficial/unauthorized**  
by CPMC or anyone on staff at the Center.

*10/21/07 TX Update: It was a dark and stormy night ...*

**No, wait. That was a different story!**

It was a beautiful day. It was one of those hot and hazy days that you get at the end of summer. And excitement filled the air. It was time again for the Annual Remsen Barn Fest! Who could ask for anything more?!

Some of you are concerned that post-tx, you will have complications and problems with medication side effects. Count on it! You sure will. But the air will go in. The air will go out. And so will you! You will go out to do things again!! You'll be alive - and you'll have fun.



In Remsen, we enjoyed the changing foliage. We saw friends and maybe made a few new ones. We bought treasures. We **didn't** eat butterfly cheese fries, or bison burgers. We didn't buy fudge, but we did buy a handmade terracotta bird feeder.

### ***Staff News:***

*Dr. Jessie Wilt, Transplant Pulmonologist:* Will be on leave starting January 1st to await the birth of her next child.

*Theresa Lukos, Transplant Pharmacist:* Will be on leave starting in December to await the birth of her child.

*Phyllis Sachs via Judy's recent update:* I went to the Thursday support group and Laurie ran it. Phyllis will be out on medical leave for about two months and a fellow named **Barrett Gray** will be filling in. The messages will still be left on Phyllis's phone.

*Sophia Brown, Financial Coordinator:* Has left the program to go back to school. We will certainly miss her! She has been a source of education and support to all of us sorting out the financial information surrounding the transplant process. We wish her well and hope to hear news of her from time to time.

## *Patient/Friend/Caregiver News:*

*Dry Runs:* Dave S. reports that he has had a dry run. And Patty B. has had a couple. Judith C. reports 2 dry runs! She's the one that the Malverne Police rushed in by closing the L.I.E. [Don't call the hospital to get them to do that for you! They don't have the authority!!]

*Angel [from Mother Sandy]:* Sorry I haven't been around, but my computer crashed. Angelina is doing GREAT!!!! No problems as of yet. She had a little staph but cleared it right up. (It is good to be young, I guess.) She is enjoying her new life and playing with her daughter, going to the park playing on the swings (something Angel could never do before!) We only go to N.Y. once a month, and soon coming up on our 6mo. check. (I'm hoping to get a 3month break, so I don't have to drive in the winter.) Angel is 110lbs!!! Can you believe it? Great big smiles and one good-looking little girl again. I am beside myself on how wonderful she is doing. Well, I guess that is enough of my bragging?

*Pete/Angela C.:* Pete says that Dr. Wilt is concerned about all the vertebra fractures. She wants to see us next week and also consult with an endocrinologist if she could speed up the bone density. Ang had another back disc cemented it's really helped. Back down for stomach x/ray as pain meds. bother her. [Ed. note: Angela still smiles all the time!]

*Hospitalized:* Valerie B - with an infection. but is better and has been discharged: Donna Z. - hospitalized for a bit, but gaining ground again; Sheila K. - hospitalized with a little infection. Pat B. - in with an infection, but has also been discharged!

*Cora D.:* Was in NYC for her regular appointment, and is doing well. Hopes to get an exciting call soon!!

*Lou J.:* Looks great and reports that he feels just fine! ☺

*The Karens:* *Karen K.* - not having much fun yet. Getting over bronchitis and is talking options with the team about having another transplant to replace her native lung; *Karen W.* - looks great and is pushing past the usual small bumps in the road post-tx; *Karen H.* - is still waiting for her call, and is looking at also listing with the Cleveland Clinic.

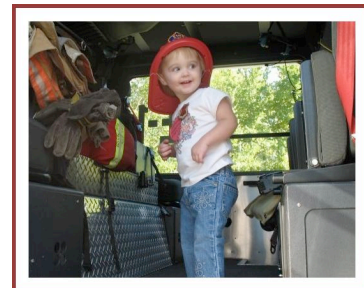
*Joan:* Hanging in there, but getting tired, Waiting for a call.

*Lois H.:* Looks good, feels pretty good – needs MORE tests! Sometimes the tests just seem endless!

*Gary G.:* On hold for stomach procedure – LATER. Enjoying his grandchildren - like Emily seen here!

*Jim H.:* Revving up for his one year check. Feels good!

*Rick D. says:* I'm on my way to points west - Colorado &



New Mexico. I have to be back for clinic on 6 November so I feel like I am rushing a bit too much - 6,500 miles in 40 days! Don't know if I'm up to doing Guadalupe Peak but I think I'm going to try it.

First test will be in a couple of days when I get to Monarch pass at 11,300 ft by Gunnison, Colorado. Should be interesting - hope I can do more than just sit around as I'm spending a few days in my old hometown near Telluride, Co..

[Barney/Grace B.](#): Grace had her annual inspection (Barney used to be a mechanic) two weeks ago. All tests came back good.

[Andy J.](#): Caregiver for Susan J. is having some cardiac issues – so he and Susan have switched roles for a bit. Andy is okay, and Susan reports that she is doing well. The daily walking really helps!

[Kathleen S.](#): The picnic was beautiful, the area was so relaxing and I gathered a lot of acorns to bring to my Stamford squirrels, met a lot of nice people and took in the magnificent views.

[Mildred B.](#): Doing well!

[Rev. Dwight Crist Northing](#): A double-lung transplant earlier this year saved the life of the 55-year-old senior pastor of the Calvary Baptist Church in Red Bank - Rev. Dwight Crist Northing. He says the experience has taken his faith to a higher level. Check the archive at Asbury Park Press for 10/8/07 to read his story:

<http://www.app.com/apps/pbcs.dll/frontpage>



### ***Our Resources:***

[Jay's site](#): Most of you know Jay. His website is invaluable to all of us in the support group. It covers topics and provides links to a multitude of articles, documents and audio/video links. It is the Unofficial Columbia University (aka NY Presbyterian) Medical Center Lung Transplant Support Home. *It is completely and totally unofficial/unauthorized by CUMC or anyone on staff at the Center.* [You can email Jay (Airmont@GMail.com) with any suggestions, additions, or comments] The site includes web pages of interest, new & newsworthy items, archives, the Support Meeting Schedule, useful links & documents. Check it out!

<http://www.lackritz.net/>

[Mike's board](#): I made this site for all of us to come and share our stories. It's about life, transplant, websites, cooking, entertainment, anything you want it to be. I hope you register and join us. We can all share experiences of what we learned at the meetings and keep a database of the handouts for downloading. This will be much easier than email but

you can choose to have the posts emailed to you as well. You can have a private conversation with the PM button or post publicly to share with everyone. Remember that this site is not endorsed by CPMC. It is for informational purposes only and you should NOT seek medical advice on this forum.

I hope to have chats with all of you in the future - lostreception (Mike)

<http://lungtx.lostreception.com>

Joann's board: Joanne Marie Schum is the youngest of seven siblings of George and Katherine Schum. Growing up in the Rochester, New York area with Cystic Fibrosis (a genetic lung illness), Joanne led a rather normal life, attending college, working in her chosen career field and being with friends and family.

As she reached her mid twenties, life became increasingly more difficult until it was nearly impossible to maneuver and have any quality in her life. That is when a lung transplant became the top priority in her life. She temporarily relocated to Chapel Hill, North Carolina while waiting for a bi-lateral lung transplant. She received her much anticipated transplant at the University of North Carolina Hospitals Chapel Hill, on **September 12, 1997**. Her lung transplant has allowed her to become involved with many organizations: volunteering as a speaker; writing for various Cystic Fibrosis and lung transplant newsletters; board member; and mentor.

*Her MSN board is used by hundreds of lung transplant recipients and listed patients world-wide. There is a message board, nightly chatroom, articles and more info than you ever dreamed possible! ☺*

<http://groups.msn.com/TransplantSupportLungHeartLungHeart>

### **Support Group Schedule:**

Please call 212-305-6266, in case the meeting is moved to a different room.

Thurs., 10/25, 1-3pm (H)	Genevieve Riley: Life after transplant
Sat., 10/27, 8:30am-4:30pm	COPD 2007-Inspiration through Education [See Jay's website for details]
Mon., 11/5, 4-6pm (H)	Speaker to be announced
Tues., 11/13, 4-6pm (H)	Brenda Klein, RD Transplant and Nutrition
Thurs., 11/29, 1-3pm (H)	Speaker to be announced
Tues., 12/11, 4-6pm (H)	Dr. Steven Kawut, MD Post Transplant Testing
Wed., 12/19, 4-6pm (H)	Dr. David Lederer Research Studies for the Lung Transplant Patient
Thurs., 12/27, 1-3pm (H)	Speaker to be announced

# TRANSPLANT CAREGIVERS FORUM

An opportunity to interact with other caregivers and support one another.  
Relevant information to help in coping with the caregiving experience.

*Topic-based discussions are repeated four times a year.*

Thurs., Oct. 25 1: Introduction To Caregiving

Thurs., Nov. 8 2: Balancing Demands and Resources

\*\*\*\*NO MEETING THURS., NOV. 22<sup>ND</sup> DUE TO THANKSGIVING HOLIDAY\*\*\*\*

Thurs., Dec. 13 Special Session: Caregiving and the Holidays

Thurs., Dec. 27 3: Shifting Family Roles/Responsibilities During TX

Thurs., Jan. 10 4: Determining the Effects of Illness On Family Communication

Thurs., Jan. 24 5: Recognizing the Signs and Symptoms of Stress

Thurs., Feb. 14 6: Managing Stress Differently, Drawing Together the Group Experience

Second and Fourth Thursday of every month 4:00-5:30pm  
New York Presbyterian Hospital-Columbia  
Milstein Hospital Bldg. 177 Fort Washington Ave.  
7HS Reemtsma Conference Room

For more information, please contact Kimberly Morse, LMSW (212) 305-3081

Comment/concerns/questions, just call or email:

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